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Alzheimer's: On Course to be the Leading Public Health Crisis of the 21st Century

Today, the effects of Alzheimer's disease are devastating – to the estimated 5.3 million Americans with the disease, to their more than 11 million caregivers, and to the nation as a whole as we all share the tremendous costs of contending with the Alzheimer crisis.

Tomorrow, the devastation of Alzheimer's disease will grow far worse. In fact, it is on course to be our country's leading public health crisis of the 21st century, and the defining disease of the Baby Boom generation. If we don't succeed in changing the trajectory of this disease, by the middle of the century as many as 16 million Americans could have Alzheimer's.¹

We can make highly confident projections about the future growth of Alzheimer cases because these estimates are directly rooted in the broad demographic transformation underway, the graying of America. While Alzheimer's is not a normal part of aging, age is the largest risk factor for the disease. One in eight Americans over 65 have Alzheimer's; age 85 and above almost one in two Americans have the disease.² And so as our nation continues to age rapidly over the coming years – the first Baby Boomer turns 65 in just 23 days – Alzheimer cases will begin to mount at an ever increasing pace. Without the discovery and delivery of effective interventions, ten million American Baby Boomers will develop Alzheimer's disease.³ And the lives of many millions more will be upended by the emotionally, physically and financially draining toll of caring for them.

But how concerned should we be with these trends? The numbers are large, but do they represent a true crisis? To candidly pose a question no doubt on the minds of some, Is Alzheimer's really as bad as the diseases many think of most often as public health crises? Those familiar with Alzheimer's know the answer to this question to be a resounding "yes."

Too many Americans are still unaware of the true, devastating impact of this disease. We are changing this, but harmful myths persist, and they must be challenged because they are partly responsible for the fact that our nation has neglected confronting this disease for far too long.

Perhaps the most pernicious of these lingering societal myths is that Alzheimer's is "just a little memory loss." As those of you who, like me, have personally witnessed loved ones suffer the impact of this disease know all too well, nothing could be further from the truth. Alzheimer's is a progressive, degenerative and ultimately fatal disease. It is cruel, and it is a killer. It kills by insidiously clogging and destroying the most vital of organs – the brain. In fact, it is one of the surest killers we know of. If you develop Alzheimer's we can say with absolute certainty that you will either die with it or from it. Alzheimer's is already the sixth

¹ Alzheimer's Association. 2010 Alzheimer's Disease Facts and Figures. Available at: http://www.alz.org/alzheimers_disease_facts_and_figures.asp

² Alzheimer's Association. 2010 Alzheimer's Disease Facts and Figures.

³ Alzheimer's Association. 2008 Alzheimer's Disease Facts and Figures.

leading cause of death in this country and, of the ten leading causes of death, is by far the fastest growing. According to the Centers for Disease Control and Prevention, Alzheimer deaths increased by more than 50% from 2000 to 2007, the most recent year for which data are available. In 2007, Alzheimer's killed more Americans than diabetes, and more than breast cancer and prostate cancer combined.⁴

If you look at the top ten causes of death in America today, you notice something else that is very striking, and very alarming. Alzheimer's is the only one of the top ten causes of death in the United States that remains without effective therapies, treatments, or preventative strategies. This must change. And it will, when we recognize this disease for the threat it is and respond accordingly.

Another aspect of Alzheimer's is its effect on others. It upends the lives of caregivers almost as surely as it does for those with the disease itself. Caregiving for Alzheimer's can literally take everything a caregiver has to give. Many caregivers experience negative health effects associated with caregiving.⁵ The manifestation, the degeneration and the progression of the disease varies with the individual, but the broad outlines are the same. If diagnosed early after symptoms first appear, the individual with the disease often can continue to enjoy a positive and functional (though impaired) life for a time; sometimes even for a few years. However, the individual will progressively lose functions until caregivers must be available 24 hours a day, at home or in a residential care facility.

In one study of family caregivers, 59 percent of caregivers felt as though they were "on duty" 24 hours a day during the last year of life for the person with dementia. 72 percent acknowledged that "they experienced relief when the person died."⁶ A National Alliance for Caregiving and AARP study found two-thirds of employed family caregivers of people with Alzheimer's and other dementia's had to go in late, leave early or take time off because of caregiving. Another study showed that caregivers of people with Alzheimer's or other dementia were 31 percent more likely to reduce hours or quit work altogether when caring for someone without behavioral symptoms when compared to caregivers of other older people. For the similar group of individuals caring for someone with behavioral symptoms of Alzheimer's or another dementia, the comparative likelihood of needing to reduce hours or to quit a job was 68 percent.⁷

America's Economic Toll from Alzheimer's

The economic factors of Alzheimer's rival the human devastation of the disease. According to the Alzheimer's Association's report, *Changing the Trajectory of Alzheimer's Disease: A National Imperative*, we are currently spending \$172 billion annually on Alzheimer's and other dementia care in America. \$88 billion of that is for Medicare alone, which is 17 percent of the total Medicare budget. Medicare beneficiaries with Alzheimer's or another dementia cost the system three times more than otherwise comparable individual in Medicare who does not have a dementia.⁸ For Medicaid, the cost multiplier for someone with dementia is nine times more than a comparable individual.⁹

Alzheimer's also serves as a cost multiplier for other conditions. 95% of Americans with Alzheimer's or another dementia have one or more other serious medical conditions as well. Largely because Alzheimer's strips away an individual's ability to manage other conditions such as diabetes or cardiovascular disease

⁴ "Deaths: Final Data for 2007." National Vital Statistics Report Vol. 58, No. 19. National Center for Health Statistics, 2010 <http://www.cdc.gov/nchs/fastats/deaths.htm>

⁵ Maria Shriver and the Alzheimer's Association. The Shriver Report: A Woman's Nation Takes on Alzheimer's. 2010. <http://alz.org/shriverreport/index.html>

⁶ Alzheimer's Association, 2010 Alzheimer's Disease Facts and Figures

⁷ Alzheimer's Association, 2010 Alzheimer's Disease Facts and Figures

⁸ Alzheimer's Association, *Changing the Trajectory of Alzheimer's Disease: A National Imperative*

⁹ Alzheimer's Association, 2010 Alzheimer's Disease Facts and Figures

successfully, the costs of care for people with these other conditions are far higher when they also have dementia. For instance, average per person Medicare payments for a person with diabetes are \$12,979, but for a person with both diabetes and Alzheimer's or another dementia average annual costs are \$20,655. The same is true for heart disease – those with only heart disease have average Medicare claims of \$14,640, while those that also have Alzheimer's or another dementia have annual costs of \$20,780.¹⁰

The *Trajectory* report estimates that during the next 40 years, the cost of Alzheimer's and other dementias will exceed \$20 trillion. Millions will get Alzheimer's and other dementias, and millions will suffer. Millions more will care for them and will suffer in different ways. So, Alzheimer's is going to cost us \$20 trillion¹¹ and all we will have to show for it are the long list of the dead, personal heartbreak, and the other devastating effects on caregivers and families.

Our country is engaged in a collective and very appropriate conversation about what should be done to address our current fiscal situation. What is notably absent from these discussions – and particularly in conversations about Medicare and Medicaid – is a systematic examination of the cost drivers behind our anticipated out-year liabilities. When we look at how we can take costs out of the system while improving outcomes, much as any successful manager might look to reduce the costs and improve the efficiency of a business operation, we quickly see that Alzheimer's should be a core part of these Medicare discussions.

Alzheimer's Association commissioned research again backs this up. The Association retained a health economics team at Dartmouth University to examine the costs of Alzheimer's and other dementias in Medicare claims data. Then, we commissioned The Lewin Group to build upon this analysis with an economic model that produced not just the future economic costs reported in the *Trajectory Report*, but also the savings our country could expect with incremental research advances. Among other findings, the model demonstrated that a therapeutic intervention that led to even a five year delay in onset would cut the projected cost of Alzheimer's over the coming decades almost in half.¹²

Voluntary Efforts to Overcome the Alzheimer's Crisis

Given the dimensions of this challenge, what's to be done about it? Particularly in these difficult times, no one would propose relying solely on the government to solve this crisis. A core part of the solution must, and should, be the voluntary efforts of Americans across the country.

That is why the Alzheimer's Association exists: to organize and apply this voluntary commitment to overcome this crisis in as compassionate, effective, and strategic a manner as possible. From my vantage point with the leading voluntary health organization in Alzheimer care and support, and the largest nonprofit funder of Alzheimer research, I am pleased to report that the commitment of volunteers is not just alive and well throughout our country, but is making a tremendous contribution to addressing the crisis just described.

The mission of the Alzheimer's Association is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's and, since 1980, we have moved toward this goal by advancing research and providing support, information and education to those affected by Alzheimer's and related dementias. We provide information and care consultations at all stages of the disease – and are available to do so every hour of the day, every day of the week, every week of the year. Across the country, we provide

¹⁰ Alzheimer's Association, 2010 Alzheimer's Disease Facts and Figures

¹² Alzheimer's Association, Changing the Trajectory of Alzheimer's Disease: A National Imperative

¹² Alzheimer's Association, Changing the Trajectory of Alzheimer's Disease: A National Imperative

support groups and other community interventions to make a difference in the lives of those who have the disease and those who are affected by it.

To find the ultimate answers to the disease, we fund cutting-edge research in top laboratories around the world. The Alzheimer's Association's peer-reviewed research grant program has awarded more than \$279 million to 1,900 scientists since 1982 – making the Alzheimer's Association the largest non-profit funder of Alzheimer research. Through partnerships and funded projects, the Association has been part of every major research advancement in the field over the past 30 years. We support novel approaches that drive new thinking. We fund science aimed at treatment and diagnosis as well as psychosocial interventions. And, we annually convene the largest research meeting in the world, the Alzheimer's Association International Conference on Alzheimer's Disease (AAICAD), drawing together the global Alzheimer research community to advance the science.

But American volunteers cannot solve this crisis alone. While the best way forward will include public-private partnerships and collaborations with organizations like the Alzheimer's Association, our government must do far more than it does today. It is what the American people clearly expect. According to a report that the Alzheimer's Association recently released with Maria Shriver, *The Shriver Report: A Woman's Nation Takes on Alzheimer's*, 78% of all respondents believe that it is “the responsibility of the government to help find a cure for a way to prevent Alzheimer's.” Almost no one—only 7% of the U.S. population—believes a great deal of progress is being made to find a cure. Compared to how much progress they think is being made in heart disease, cancer, diabetes, and strokes, Americans rank Alzheimer's dead last.¹³

And so, in addition to our work in care and research, the Alzheimer's Association is also expanding our efforts in advocacy, fighting for critical Alzheimer research, prevention and care initiatives at the state and federal level, all driven by an aggressive, strategic approach to overcoming this disease as quickly, effectively and efficiently as possible.

How the Government Can Effectively Address this Crisis

Working with Alzheimer champions in the House and Senate, the Alzheimer's Association has collaborated in the drafting of three critical pieces of legislation that together would dramatically transform our national stance toward this disease and generate bold, strategic action. These three bills are the *National Alzheimer's Project Act*, the *Alzheimer's Breakthrough Act*, and the *Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act*.

Planning: The National Alzheimer's Project Act

We are heartened that the first of these bills, the *National Alzheimer's Project Act* (NAPA), is poised for passage in the remaining days of this Congress. We ask your support for this critical legislation.

Our federal government currently has no systematic plan to overcome Alzheimer's. No plan for investing in research to stop it. No plan to handle the cost of care if it isn't stopped. No plan for having enough residential care facilities for that inevitable point in the disease process when even the most dedicated caregivers can no longer handle the care at home, or a plan for new approaches to homecare. We have no articulation of objectives, timelines, assignment of responsibilities or any of the routine hallmarks of disciplined, effective management. Despite the millions of American lives and the trillions of American dollars at stake, we are drifting into the future rather than marching to a clear destination.

¹³ Maria Shriver and the Alzheimer's Association. *The Shriver Report: A Woman's Nation Takes on Alzheimer's*. 2010.

Building on the recommendations of the Alzheimer's Study Group, an independent, bipartisan panel created to evaluate the government's current efforts to combat the disease, NAPA would create a national strategic plan for the Alzheimer's disease crisis. It would also establish an inter-agency council to work with the Secretary of Health and Human Services to comprehensively assess and address Alzheimer research, care, institutional services, and home and community based programs. NAPA would ensure strategic planning and coordination of the fight against Alzheimer's across the federal government as a whole.

The Alzheimer's Study Group called for this action by 2010, and NAPA would set it in motion. Thanks in part to the leadership and foresight of members of this committee together with other members of the House and Senate, we appear on track to hit this mark.

Research: The Alzheimer's Breakthrough Act

But with what we hope and expect will be the passage of NAPA in this Congress, we must turn to the glaring fact that what's most needed in Alzheimer's is investment in more research to change the course of the disease as soon as possible. The science community is upbeat about the potential for Alzheimer advances, but as the boomer generation ages to the point of what is considered the earliest age of typical onset, 65, we need to act now.

Based on the most recently available data, federal funding for cancer is about \$6 billion, for cardiovascular diseases about \$4 billion, and for HIV/AIDS about \$3 billion. These have all proven to be smart, important investments that should continue based on their high returns in lives saved.¹⁴ By contrast, not counting the one-time stimulus funds, total federal funding for Alzheimer research is currently just \$469 million.

We already spend \$25,000 in care costs for every \$100 we spend on Alzheimer research.¹⁵ By the middle of the century, we will spend more than \$1 trillion annually for care for Alzheimer's and other dementias if we don't change the course of the disease.¹⁶ Those care costs are not due to inflation—the costs are in today's dollars.

The *Alzheimer's Breakthrough Act* would begin to address our woefully shortsighted underinvestment in Alzheimer's research. As investment in other diseases such as cancer, heart disease and HIV/AIDS demonstrates, adequate medical research investment more than pays for itself, not just in improved quality of life for those with Alzheimer's and their caregivers, but for the economic health of the country as well.

Care and Support: The Health Outcomes, Planning and Education (HOPE) for Alzheimer's Act

Yet even if we increase our investments, we cannot simply wait for the breakthroughs that will one day end Alzheimer's. Research takes time to yield results and in the meantime there is much we need to do to improve care and support for those contending with this disease.

Today, our health system does not work well for Alzheimer's care and support. The HOPE for Alzheimer's Act would make immediate contributions to the lives of the more than five million Americans with the disease today and their caregivers.

¹⁴ National Institutes of Health, Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), 2010. <http://report.nih.gov/rcdc/categories/>

¹⁵ Alzheimer's Association, 2010 Alzheimer's Disease Facts and Figures.

¹⁶ Alzheimer's Association, Changing the Trajectory of Alzheimer's Disease: A National Imperative.

To provide better medical care and outcomes for individuals with Alzheimer's and other dementias, the dementia must first be detected, the disease causing it must then be diagnosed, care must be planned, and the diagnosis must be noted in the patient's medical record.

Figures on diagnosis differ, but it is likely that less than half of people with dementia have been formally diagnosed. Worse, although African-Americans and Hispanics are more likely than whites to have Alzheimer's and dementia¹⁷, studies conducted in physician offices and clinics show that African-Americans and Hispanics are less likely than whites to have a diagnosis of the condition.

If enacted, the HOPE for Alzheimer's Act will increase detection and diagnosis of dementia in primary care settings necessary for the provision of critical information and referrals to support services. It will also insure that Medicare beneficiaries have access to a package of services that will include a diagnostic evaluation, care planning and medical record documentation. Finally, it will help individuals with newly diagnosed dementia and their family caregivers understand the diagnosis, plan for predictable problems, avoid crises, and maintain the best possible quality of life.

The HOPE for Alzheimer's Act will deliver important improvements in outcomes and serve as a strong foundation for subsequent efforts to improve Alzheimer's care and support. We must lay this foundation as quickly as possible.

Hope for the Future – If We Act Quickly and Decisively Today

I get the benefit of exposure to scientists working worldwide to end this disease. I also have the opportunity to see so many others dedicated to providing care and support to those who will have the disease before we finally end it, and all of the volunteers, staff and donors who advance the mission of the Alzheimer's Association each and every day. Because of their collective energy, I remain optimistic about Alzheimer advances. I believe that we will succeed. We *must*.

I'm confident that we will prevail against Alzheimer's. It's not a matter of "if," it's a matter of "when." But "when" needs to be sooner rather than later. It's too late for my mother, and it's too late for the millions more who have died or who have progressed too far in their disease. Until we realize our vision of a world without Alzheimer's, the Alzheimer's Association will keep pursuing every possible approach to support those facing the disease and every possible way to find the answers we need to end it.

On behalf of the millions I represent this morning, I ask for your leadership in securing the success we need to address Alzheimer's, a true public health crisis for America.

Thank you.

¹⁷ Alzheimer's Association, 2010 Alzheimer's Disease Facts and Figures.